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Alzheimer's Disease State Plan Task Force
Meeting #2
Thursday, January 28, 2010

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In Attendance:
Jerry Dowell, Maureen Dempsey, Carroll Rodriguez, Jean Leonatti, Theresa Valdes, Gwen Richards, Glenda Meachum-Cain, Lisa Baron, Lois Zerrer, Lynn Carter, Maria Chapelle-Nadel, Deb Ellis, Joan D'Ambrose, Julie Ballard, Tim Dolan, Patrick Lynn, and Jason Echols

Review of Community Forums – Dates
HB 272 calls for 4 community forums and, at the last taskforce meeting, a 5th was added for Cape Girardeau. Community forums are separate from taskforce meetings. Taskforce members will be sent a flyer with all finalized dates to send to their respective email lists.

(Taskforce members indicated their initial availability to attend different community forums. The list of taskforce members attending each forum is tentative.)

Columbia – *Already Held*
    January 27, 2010
    5 to 7pm
    Lenoir Woods Community Center in Columbia
    Facilitator: David Oliver PhD, UM School of Medicine

Saint Louis
    Tentative Location – Alzheimer's Association, St. Louis Chapter, 9370 Olive Street
    March 25, 2010
    5:30 to 7pm
    Contact: 314.432.3422
    Facilitator: Ann Steffen PhD

    Taskforce Members: Jerry Dowell, Carroll Rodriguez, Jean Leonatti, Theresa Valdes, Gwen Richards (tentative), Glenda Meachum-Cain, Lisa Baron, Lois Zerrer (tentative), Lynn Carter, Maria Chapelle-Nadel, Deb Ellis, Joan D'Ambrose, Julie Ballard, Tim Dolan, and Patrick Lynn

Springfield
    Drury University, Trustee Science Center, Reed Auditorium,
    March 31, 2010
    6 to 8pm
    Contact: 417.886.2199
    Facilitator: Todd Parnell, President, Drury University

    Taskforce Members: Jerry Dowell, Jean Leonatti, Theresa Valdes, Glenda Meachum-Cain, Lois Zerrer, Lynn Carter, Maria Chapelle-Nadel (tentative), Deb Ellis (tentative), Joan D'Ambrose, Julie Ballard

Kansas City
    Bruce R. Watkins Cultural Center 3700 Blue Parkway, Kansas City, Mo. 64130.
    April 8, 2010
    4 to 5:30pm
    Contact: 913.831.3888
    Facilitator: Nick Haines – Executive Producer of News & Public Affairs
     Programming – KCPT

    Taskforce Members: Jerry Dowell, Carroll Rodriguez, Theresa Valdes, Gwen
      Richards, Glenda Meachum-Cain, Lisa Baron, Lois Zerrer (tentative), Maria
      Chapelle-Nadel, Julie Ballard, Tim Dolan, and Patrick Lynn

Cape Girardeau
    Tentative date is April 5
    Taskforce Members: Jerry Dowell, Carroll Rodriguez, Joan D'Ambrose, Julie
      Ballard, Tim Dolan

Taskforce Feedback on Columbia Community Forum:
- Need a handout to give background info to forum participants, and include:
  - Brief description of taskforce and its purpose
  - Names of taskforce members and description of position held
  - Web site/state's blog address and other contact information
- Future forums will have a staffed resource table a taskforce member could join as well
- Liked the setup of going from table to table
- Liked facilitator ease of subject knowledge
- Carroll Rodriguez's presentation:
  - Include background on taskforce
  - Leave up the last slide with the three questions throughout forum to guide discussion
- Hold comment/questions from taskforce until end
- Important to acknowledge and thank community members and let them know that people on the taskforce know what they are going through (e.g., Gwen's comments)
- All forums should be expanded to 2 hours at a minimum
- Comments from forums can be included as a prologue to the final report
- Jason will analyze comments from community forums to code for frequency, geographic distribution, etc.

St Louis – Next Taskforce Meeting – March 25
- It was decided that not all community forums will be accompanied by a full taskforce meeting, but the Saint Louis community forum will also have a taskforce meeting.
- To accommodate those with limited travel budgets the meeting will take place from 1-5 pm on March 25, the same day as the forum.
- Meeting will include educational presentations on: Project LEARN and MemoryCare Home Health Solutions.

- o   Future educational presentation: Culture Change and MC5
- OPTIONAL morning tour of local services: PACE program, Dolan Residential Care facilities
  - o   Tour of Veteran's Home is tabled until Cape Girardeau where there is a facility
- Maria's intern is working on a communication/outreach plan and will reach out to minority population facing AD in St Louis area

Survey Option for Feedback Beyond Forums
- Online survey as a way to get feedback from those not at the community forums
- Take feedback from the five forums and distill themes – use online survey to get feedback on how people prioritize their needs and prioritize the services/interventions that they have been able to use
- Avoid open-ended questions so that there is not copious amounts of information
- Open it in April after forums
- People to work on it: Lisa, Jason, and Maria's intern

Other
- Report due in Nov 2010 but taskforce will continue to follow through until 2012 on following up with these recommendations through drafting legislation, working with state, etc.
- Both Quality and Services Workgroups should be looking at hospitals.
- National Alzheimer's Association has researched federal laws and the current healthcare reform to analyze the impact on Alzheimer's – Joan will share with the group

Workgroup Reports
Services
- Members in attendance: Jean Leonatti (chair), Carroll Rodriguez (co-chair), Lisa Baron, Lynn Carter, Glenda Meachum-Cain, Gwen Richards, Theresa Valdes, Lois Zerrer
- See attached minutes

Quality of Care
- Members in attendance: Maureen Dempsey (chair), Julie Ballard (co-chair), Joan D'Ambrose, Tim Dolan, Jerry Dowell, Deb Ellis
- See attached minutes

Research
- John Morris (chair)
- Did not meet today
- Carroll will forward the Kentucky state report to John Morris and Maureen Dempsey to review the categories/stages of disease progression.

Services Work Group Notes
Alzheimer's Disease State Task Force
1/28/2010, 8:30am

Those in attendance: Theresa Valdes, Gwen Richards, Glenda Meachum-Cain, Lisa Baron, Lois Zerrer, Lynn Carter, Jason Echols, Ashley Burden, Carroll Rodriguez, Jean Leonatti.

There was consensus on the following items:

Our charge:
- Identify generally available services in the state, including average costs and payment sources
- Identify gaps in services based on information from Community Forums and literature search on "evidence-based practices"
- Identify barriers to obtaining services

We will use these major categories to group services:
- Community/home-based services – includes diagnosis, screening, early awareness, planning, as well as traditional services
- Residential/Institutional services – includes assisted living, residential care facilities, skilled nursing, hospitals, emergency rooms, gero-psych units
- Caregiver support

There was also consensus that we want to include in the report introduction core principles for all the services. We might look to the Kentucky state report for formatting and staging (i.e., stages of disease progress) suggestions. We agreed that either the Research or the Quality Work Group should take the lead on defining the stages of dementia; we will have opportunities for review and comment, but it was important that all three work groups utilize the same staging criteria.

We then began a "brainstorming" session on services:

Community/Home-based Services:
- Project LEARN --- early intervention with care consultation for families to assist in planning and awareness of available services
- Respite care
- Personal care
- Homemaker/Chore
- Home-delivered meals
- Adult Day Care – a gap in rural areas; primarily available in larger cities
- Transportation – group transportation available statewide; individualized is spotty
- Information and referral
- Home Health
- Legal/financial advice – generalists are readily available; but specialists aren't

- Comfort Zone/MedicAlert Safe Return (Alzheimer's Association)
- Gap – people don't know about services and resources
- Gap – physicians aren't providing information on available services/supports to newly diagnosed
- Gap – Behavior interventions/modifications, gero-psych
- Gap – Safety for victims (medic alert, GPS, etc.), public safety officer training
- Barrier – Medicaid only pays for respite with a waiver (only available to people 63+)

At next meeting, committee will brainstorm on the other two service categories.

Homework assignments:
- Jean and Jason will finalize notes and send them out; members are to use those to stimulate additional listings
- Glenda will circulate the literature search she had already completed
- Glenda will check on hospital gero psych unit regulations (DHSS)
- Carroll will send out web-link for the Kentucky state report
- Carroll will figure out some cost components
- Lynn will research behavior intervention services for dementia patients and circulate
- Lynn will research the Florida hospital initiative
- Theresa will catalogue Medicaid services available for this population, average cost and usage, etc.

Meeting adjourned at 10:00 am to participate in the full Task Force meeting.

Quality Work Group Notes
January 28, 2010
Submitted by M. Dempsey, MD, Chairperson

Many of the subheadings under the discussion headings (highlighted in another color) were drawn from other state plans or recommendations. I reviewed the other plans and thought that these were relevant and could serve as a starting point for our continued discussion - Illinois, Iowa, Kentucky, Michigan (items in basic black text are from our discussion). Review of other plans has not been exhausted. Additional research for other sources and resources remains to be pursued in depth.

1. Continuum of care – The research group should define for all subcommittees. Once we agree to the elements of the continuum, all groups can align their recommendations accordingly.
   a. Stages – identification of them – research committee
2. Barriers
   a. Many barriers have been identified, can agree upon what to pursue and timing of pursuit.
   b. These can be aligned according to the continuum in order to inform appropriate interventions during each phase of progression from prevention until late stage.
3. Gaps
   a. These are well known – and consistent from state to state, family to family, etc., and coincide with the barriers.
   b. Additional information can be gleaned from the community forums – can be grouped according to "themes".
   c. Need to identify, list and coordinate/integrate all recommendations in order to fully address.
4. Number of geriatricians
   a. Need to increase and foster education, recruitment, training and reimbursement
   b. Regulation for geriatric expertise in specialized units
   c. May not be a sufficient number of formally trained geriatricians, so will also need to address the experience and expertise of primary care providers – such as FP, IM, GP, Psychiatry, nurse practitioners, etc.
5. Regulations
   a. Need to review current licensure requirements, AD unit designation, training requirements
   b. Need to review how accountability is assured, measured, monitored, reported.
   c. Need to review how certain measures designed to facilitate care at the nursing home or residential level (reporting patient on patient violence, patient/staff altercations, etc may place individuals with Alzheimer's at a disadvantage or have untoward consequences.
   d. Review regulations and oversight of resident "commitment" to psychiatric units.

    e.   Review the role and responsibilities of the Division of Aging with regard to investigations into quality of care.

    f.   Review overlapping requirements for licenses for personal care homes and assisted living facilities such as medication management including oversight, assistance, administration and monitoring and recommend appropriate regulation changes to accommodate the needs of persons with dementia.

6. Staff ratios
   a. Reimbursement determines ability to provide lower ratio of staff to resident
   b. What is the correct ratio? Standards exist?
   c. How to enforce?
   d. Is there a different ratio for individuals who may also have "behavioral" issues?
   e. What best practices exist? Models of operation? Need to review and assure measurability.
   f. Cost-effectiveness and Access to appropriate settings are an issue.
   g. Staff training

7. AD unit designation and staffing
   i. How is such a designation achieved?
   ii. How do they (or do they) differ from "memory" units
   iii. What is the oversight and accountability structure?
   iv. Who defines the standards for quality of care?
   v. What are the standards for professional practice and training and expertise of medical directors of such units?
   vi. Training of staff – who, how often, how to assure appropriate expertise?
   vii. Who provides training?
   viii. Mandatory vs. minimum standard measures?
   ix. What safeguards exist for the use of "temporary" staff that may be placed on these units with inadequate training or familiarity with the residents?
   x. Size – graduated services
   xi. HUD – senior housing - $ for development or redevelopment
   xii. Raise the standards of care for entities providing care and services to any persons with Alzheimer's disease or related dementias throughout the entity, including but, not limited to, entities without AD Units, as well as, in the Non-AD Unit sections of entities with AD Units.
   xiii. Require AD Units and the Department of (Public) Health to provide consistent, publically available and accessible AD Unit information.

        xiv. Require improved accountability for care and treatment for persons living in special care units and all other entities caring for persons with Alzheimer's disease and related dementias.

              1. Require all Departments that license or certify entities with AD Units to standardize the disclosure reports, make the disclosure reports available and accessible to current and prospective residents, and the public.

8. Denials for behavioral issues
   a. Who oversights the "commitment" of residents?
   b. Who oversights and what are the regulations regarding the use of the term "a danger to themselves or others" as a means of transfer to an inpatient psych setting.
   c. Design a structure to review transfers/discharges of persons with Alzheimer's disease or related dementias in AD Units. These entities must demonstrate staff is trained to provide appropriate behavioral interventions and medications and these interventions have been tried and have failed.
   d. Apply more stringent transfer/discharge procedures for all persons with Alzheimer's disease or related dementias residing in any licensed or certified residential entity. These entities must provide proof that staff has been trained in appropriate behavioral interventions prior to the transfer/discharge.
   e. Limit the number of days that a person with Alzheimer's disease or related dementias may be absent from the entity in cases of transfers/discharges for behavioral issues.

9. Problems with diagnosis and referral – other diagnoses, delayed diagnoses

10. Hospital care in general with Alzheimer's diagnosis
    a. Training of staff
    b. Ability of family members to be present
    c. See POA issues also

11. Hospice care
    a. Cost and Access
    b. Setting – home vs. SNF
    c. Quality of care?
    d. See POA issues, also

12. POA issues – legal issue with access, continuity, coordination, selection of providers and inpatient services
    a. POA not well understood by families, hospitals, psych units and SNFs
       i. Need training and education for ALL
       ii. Need to address these issues early in AD progression for planning purposes

b. Individuals on AD units or in SNFs may be transferred and have medications altered without the consent of the individual with POA – see 8b.

c. "Commitment" and the use of the term "a danger to themselves or others" may supersede or impede actions of the person with POA to assure adequacy and appropriateness of care and for making additional medical decisions.

13. "Commitment" to psychiatric units – safety, services, lack of geriatrician, lack of standards

a. Risks need to be identified for AD individuals placed in the general psych setting

b. What are appropriate interventions?

c. Are there standards for the use of "isolation" in and individual with AD?

d. Who reviews and approves the use of "behavioral modification" techniques, mandatory group participation, goal setting and measures of judgment and insight, and defines the ability to participate in such treatment activities?

e. How do such traditional psychiatric interventions impede or assist the AD individual in returning to a less restricted or more familiar setting?

f. Should there be a time limit for how long an AD individual is in a psych setting if removed from familiar settings?

g. What are the standards of care for medical conditions while in an inpatient psych setting?
   i. Who assures basic needs such as nutrition and hygiene are met?
   ii. Who oversights?
   iii. Who coordinates?

h. Individuals with Alzheimer's may be placed at risk in settings outside of their home or residential care.
   i. Lack of familiarity with surroundings, caregivers
   ii. Lack of or prohibition of family visits due to restricted settings and hours for visiting
   iii. At risk for abuse and neglect – unable to voice complaints or protect self and unable to comprehend or comply with requests for redirection of "behaviors" or actions.

i. Families requires assistance in arranging return to facilities or identifying new facilities if return is refused
   i. Convene a workgroup of physicians and other mental health and Alzheimer's specialists to determine the adequacy of geriatric-psychiatric hospitals, both by number and location, and to establish a consensus plan outlining parameters for the type and length of treatment that should be provided to persons with Alzheimer's disease and related dementias in hospital geriatric-psychiatric units.
   ii. Determine and implement protocols for placement and release from geriatric-psychiatric hospitals.

iii. Establish protocols for community-based systems of care to meet the needs of persons with Alzheimer's disease and related dementias who exhibit behaviors requiring interventions.

iv. Expand opportunities and provide incentives for advanced education for primary healthcare providers who specialize in the treatment of persons with Alzheimer's disease or other dementias who require geriatric-psychiatric services.

v. Convene a workgroup on a regular basis to address psychogeriatric needs of persons with Alzheimer's disease. The workgroup would be tasked with identifying mechanisms for funding of in-patient mental health services, expanding the statewide availability of services, establishing education pathways for providers, and enhancing the availability of emergency crisis intervention.

vi. Require mental health parity.

vii. *Institute state policies and procedures to provide additional support to ensure the health, safety and welfare of individuals with Alzheimer's Disease and Related Dementias.*

viii. Work with law enforcement to implement a coordinated protocol or swift and appropriate action upon report of a missing adult with dementia.

ix. Evaluate state regulations on home care, adult day and home health to assure they are "dementia friendly".

x. Explore changes in the certificate of need requirements in order to foster expansions of Alzheimer's and dementia specific services.

xi. Support a pilot demonstration project to address the problem of facility discharges of residents exhibiting challenging behavior.

xii. Develop regulations or waiver protocol inviting the development of new approaches to facility design that are preserve resident safety, recognize the special needs of persons with memory loss and pursuant to evidence based practice show promise for improving the quality of their lives.

xiii. Review the "Resource Utilization Groups" (RUGs) system to determine values of behavior management and evidenced based interventions.

xiv. Increasing opportunities for self-determination.

xv. Identify challenges to admission and eligibility requirements.

14. Private pay vs. Medicaid – quality and amenities, staffing

15. Keep at home as long as possible – exhaust resources and go to SNF, where care may not meet specific needs, training for staff may not be appropriate and ratio of staff to resident inadequate.
    a. Caregiver training and resources
    b. Cost of services?
    c. What resources are available to assist families?
16. Culture Change – philosophy of care
    a. **Promote best practices in dementia detection, assessment and care management in primary care.**
    b. **Advocate for dementia-friendly policies and promote the highest quality dementia care standards in Michigan long-term care systems reform efforts.**
    c. **Increase early intervention and support for persons with dementia and their caregivers by promoting public awareness of the caregiver role and the early warning signs of dementia.**
    d. **Primary Care Initiative -** *Promote a public health, disease management approach to dementia care in primary care practice that makes full use of best dementia care practices*.
    e. Create educational modules that Primary Care Physicians could use
    f. Create a method of face-to-face instruction and interaction with Primary Care Physicians. Five educational modules were created and posted on the Coalition website, www.dementiacoalition.org (see Appendix D). These cover:
        i. Dementia in Primary Care
        ii. Community Resources
        iii. Clinical Diagnosis of Dementia
        iv. Pharmacologic Treatment of Alzheimer's Disease
        v. Reimbursement for Dementia Care
17. Person centered care
    a. See Philosophy of care
18. MC5 – Julie to provide additional information
19. Economy of scale/profits – design issues which impact care
    a. Staffing ratios, reimbursement and private pay may have better design and ratios, etc.
20. Professional education
    a. CME – mandatory number of hours by profession, per year, etc
    b. Professional educational schools – specific training during school, internship, residency, etc.,
    c. Professional standards
    d. **Consider the requirement for annual CME (specific number of hours) for geriatricians, Internal medicine, Family Practice, Psychiatry, etc., and or at least initial with periodic refresher training**

       i.   **Specific set of learning requirements**
     ii.   **Expand opportunities and provide incentives for advanced education for primary health providers who specialize in the treatment of persons with Alzheimer's disease or other dementias who require geriatric-psychiatric services.**
   iii.   Promote Alzheimer's research using incentives as necessary.
   iv.   Determine and develop the funding and other mechanisms to provide incentives to bring qualified health care providers into the community-based system of care throughout the state. These incentives may be both financial and non-financial, such as forgiveness of loans or loan repayment options, stipends, scholarships funded by the state and from other resources and relocation expenses.

e. **Establish, initiate and require basic, specialized and periodic education and training, as appropriate, for persons throughout the state whose responsibilities make it likely that they may come into contact with persons with Alzheimer's disease and related dementia.**

f. **Establish and initiate training protocols for all persons who come into contact with persons with Alzheimer's disease and related dementias**, including, but not limited to, first responders, state service personnel (i.e. Division of Motor Vehicles), and others in the community, as well as those in health care settings. Improve the skills and review and increase training for caregivers, medical specialists and generalists. Specific training in behavioral interventions for persons with dementia exhibiting challenging behaviors should be required for professionals and those in health care settings and encouraged in other settings.

g. Explore the concept of linking diagnostic codes at the hospital with reimbursement and level of training.

h. Limit the use of hospital geriatric-psychiatric units to temporary stays for the most extreme cases only after all behavioral interventions are explored and, if appropriate, used.

i. Identify the areas where community-based systems of care would be most beneficial to persons with Alzheimer's disease and related disorders with behavior issues beginning in those areas without access to any such services.

j. Review the distribution of geriatric-psychiatric units. Permit the development of such

k. Units only in greatly underserved areas without such units and only if it can be demonstrated that the needs of the population cannot be met through a community-based system of care.

l. Establish or broaden the number of hours for training for direct care staff to a minimum of 8 hours classroom instruction and a minimum of 8 hours of supervised interactive experience.

m. Establish or broaden the number of continuing education/in-service hours for direct care workers on the topic of Alzheimer's disease or related disorders to a minimum of 8 hours annually.

n. Add a competency component following Alzheimer's disease or related disorders training.
o. Establish a standard curriculum model that will include, but not be limited to: the diagnostic process, the progression of the disease, communication skills (including the person with the diagnosis, family, friends and caregivers), family stress and challenges, nutrition and dining information, activities, daily life skills, caregiver stress, the importance of building relationships and understanding the personal history, expected challenging behaviors and non-pharmacologic interventions, and medication management.
p. Establish a certification process for trainers and educators of the standard curriculum model.
q. Broaden the spectrum of people who are required to receive training specific to Alzheimer's disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer's disease including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for long term care oversight/monitoring, and ombudsmen.
r. Create an optional specialized certification for health and human services professionals to provide quality care and improve the quality of life for people with Alzheimer's disease or related disorders.
s. Increase the spectrum of educational resources available by using on-line courses, community colleges and make subsidized educational opportunities available for those wishing to specialize in this field.
t. Ensure that all task force recommendations coalesce with other initiatives and programs within the state.
u. Establish policies, procedures, and incentives to incorporate evidence-based practices into training, service, and program activities.
v. Research and evaluate promising practices
w. Identify specific training resources for targeted audiences across the state.
x. Develop relationships with police and community partners to develop and implement training (such as, but not excluding including but not limited to, bankers, attorneys, police, emergency personnel, etc.).
y. Develop and implement an evidence-based training curriculum and implementation strategies for targeted audiences (i.e. Department for Mental Health and Mental Retardation, Office of Inspector General surveyors, Comprehensive Care Centers, family caregivers, etc.).
z. Develop and implement an evidence-based training curriculum and implementation strategies for Long Term Care facilities.
aa. Require mandatory dementia-specific training as part of yearly in-service training for emergency personnel (e.g. firefighters, emergency medical technicians, police officers).

bb. Require mandatory dementia-specific training for emergency room staff including nurses, physicians and related services technicians such as radiology.

cc. Increase training for state adult protective services workers on Alzheimer's/dementia.

dd. Require training for providers and State staff associated with any of the Medicaid home and community based waivers.

ee. Develop a portable certification program for para-professional direct caregivers with standardized content designed to enhance their understanding of memory impairment and their performance in caring for individuals with Alzheimer's and related dementias.

ff. Work with the universities to develop specific training and recruitment options including: The development of optimal training content standards for licensed health professionals; target Kentucky's professional schools to integrate it into curricula.

gg. Create a "Bucks for Brains" program to recruit and train geriatric psychiatrists, geriatricians, and other geriatric specialists.

hh. Development of residencies or fellowships for training of geriatric psychiatrists, geriatricians, and other geriatric specialists.

ii. The development of a specific track on Alzheimer's disease related dementias and dementia related diseases for medical students and residents.

jj. *Establish policies, procedures, and incentives to incorporate evidence-based practices into dementia-specific training, service, and program activities.*

kk. Identify and promote wide use of evidence based practices through the development of an Evidence-Based Practice Guide specific to Alzheimer's Care.

ll. Explore changes needed to support the purchase and provision of evidence based practice training and education.

mm. Require and provide training and the subsequent provision of evidence based practices in programs and services supported by State funds.

nn. Identify and explore ways to further evaluate existing evidence based practices with Kentucky's populations.

oo. *Research and evaluate promising practices across various regions in Kentucky.* **Strategies:** Continue exploring grant opportunities to provide empirical evidence of nationally recognized evidence based practices

21. Quality of Life

    a. Advocate for integrated systems of healthcare and support that are effective for individuals with Alzheimer's disease or related dementias and their families. (e.g. disease management strategies, practice guidelines, home and community based care, hospice care and chronic care management).

22. Quality of care

    a. Develop, implement and coordinate a statewide data collection system.

23. Respite care

        a. Request an increase in the Alzheimer's Respite Services budget

24. Prescription cost
25. Family training – caregiver training
        a. Awareness – general for planning and for families to comprehend and assist with needs
        b. Increase and improve support for family caregivers.
26. Affinity fraud – MO SAFE, $ fraud
27. AD8 – Jim Galvin